

**Ersek, M, Smith, D., Cannuscio, C., Richardson, D.M., Moore, D. A nationwide study comparing end of life care for men and women Veterans. Journal of palliative medicine 2013 16(7): 734-740.**

*Background:* The quality of end-of-life (EOL) care at Veterans Affairs Medical Centers (VAMC) has improved. To date, however, the quality and outcomes of end-of-life care delivered to women veterans have not been examined.

*Objective:* The goal of this study was to evaluate gender differences in the quality of EOL care received by patients in VAMCs nationwide.

*Design:* The study was conducted via retrospective medical chart review and telephone survey with next of kin of recently deceased inpatients.

*Setting/subjects:* The chart review included records for all patients who died in acute and long-term care units in 145 VAMCs nationwide ( $n=36,618$ ). For the survey, the documented next of kin were invited to respond on behalf of the deceased veteran; a total of 25,638 next of kin completed the survey.

*Measurements:* Chart review measures included five indicators of optimal end-of-life care. Bereaved family survey items included one global and nine specific items (e.g., bereavement care, pain management) describing care in the last month of life.

*Results:* Receipt of optimal end-of-life care did not differ significantly between women and men with respect to frequency of discussion of treatment goals with a family member, receipt of palliative consult, bereavement contact, and chaplain contact with a family member. Family members of women were more likely than those of men to report that the overall care provided to the veteran had been “excellent” (adjusted proportions: 63% versus 56%; odds ratio (OR)=1.33; 95% confidence interval (CI) 1.10–1.61;  $p=0.003$ ).

*Conclusions:* In this nationwide study of all inpatient deaths in VAMCs, women received comparable and on some metrics better quality EOL care than that received by male patients.

**Casarett, D., Pickard, A., Bailey, F.A., et al. A nationwide VA palliative care quality measure: The Family Assessment of Treatment at the End-of-Life. J Palliative Med 2008; 11: 68-75.**

*Objectives:* To evaluate the FATE (Family Assessment of Treatment at End of Life) Survey for use as a nationwide quality measure in the VA health care system.

*Design:* Nationwide telephone survey.

*Setting:* Five VA medical centers.

*Participants:* Eligible patients received inpatient or outpatient care from a participating VA facility in the last month of life. One respondent/patient was selected using predefined eligibility criteria and invited to participate.

*Measurements:* The FATE survey consists of 32 items in 9 domains: Well-being and dignity (4 items), Information and communication (5 items), Respect for treatment preferences (2 items), Emotional and spiritual support (3 items), Management of symptoms (4 items), Choice of inpatient facility (1 item), Care around the time of death

(6 items), Access to VA services (4 items), and Access to VA benefits after the patient's death (3 items).

*Results:* Interviews were completed with 309 respondents. The FATE showed excellent psychometric characteristics, with good homogeneity (e.g., Cronbach ( $\alpha$ ) = 0.91) and no evidence of significant ceiling effects. The FATE also demonstrated good discriminant validity. For instance, FATE scores varied across facilities (range 44–72; Kruskal Wallis test  $p < 0.001$ ). Patients who were seen by a palliative care service had better scores (mean 66 versus 52; rank sum test  $p < 0.001$ ), as did patients who were referred to hospice (67 versus 49; rank sum test  $p < 0.001$ ).

*Conclusions:* The FATE survey offers an important source of quality data that can be used to improve the end-of-life care of all veterans, regardless of the type of care they receive or their site of death.

**Casarett D.J., Pickard A.P., Bailey F.A., et al. Important aspects of end-of-life care for veterans: Implications for measurement and quality improvement. J Pain Symptom Manage 2008; 35: 115-125.**

To identify aspects of end-of-life care in the U.S. Department of Veterans Affairs (VA) health care system that are not assessed by existing survey instruments and to identify issues that may be unique to veterans, telephone interviews using open-ended questions were conducted with family members of veterans who had received care from a VA facility in the last month of life. Responses were compared to validated end-of-life care assessment instruments in common use. The study took place in four VA medical centers and one family member per patient was invited to participate, selected from medical records using predefined eligibility criteria. These family members were asked to describe positive and negative aspects of the care the veteran received in the last month of life. Interview questions elicited perceptions of care both at VA sites and at non-VA sites. Family reports were coded and compared with items in five existing prospective and retrospective instruments that assess the quality of care that patients receive near the end of life. Interviews were completed with 66 family members and revealed 384 codes describing both positive and negative aspects of care during the last month of life. Almost half of these codes were not represented in any of the five reference instruments ( $n = 174$ ; 45%). These codes, some of which are unique to the veteran population, were grouped into eight categories: information about VA benefits ( $n = 36$ ; 55%), inpatient care ( $n = 36$ ; 55%), access to care ( $n = 33$ ; 50%), transitions in care ( $n = 32$ ; 48%), care that the veteran received at the time of death ( $n = 31$ ; 47%), home care ( $n = 26$ ; 40%), health care facilities ( $n = 12$ ; 18%), and mistakes and complications ( $n = 8$ ; 27%). Although most of the reference instruments assessed some aspect of these categories, they did not fully capture the experiences described by our respondents. These data suggest that many aspects of veterans' end-of-life care that are important to their families are not assessed by existing survey instruments. VA efforts to evaluate end-of-life care for veterans should not only measure common aspects of care (e.g., pain management), but also examine performance in areas that are more specific to the veteran population.

**Casarett D.J., Pickard A.P., Bailey F.A., et al. Do palliative consultations improve patient outcomes? J Am Geriatr 2008; 56: 593-599.**

*Objectives:* To determine whether inpatient palliative consultation services improve outcomes of care.

*Design:* Retrospective telephone surveys conducted with family members of veterans who received inpatient or out-patient care from a Department of Veterans Affairs (VA) medical facility in the last month of life.

*Setting:* Five VA Medical Centers or their affiliated nursing homes and outpatient clinics.

*Participants:* Veterans had received inpatient or out-patient care from a participating VA in the last month of life. One family member completed each survey.

*Measurements:* The telephone survey assessed nine aspects of the care the patient received in his or her last month of life: the patient's well-being and dignity (4 items), adequacy of communication (5 items), respect for treatment preferences (2 items), emotional and spiritual support (3 items), management of symptoms (4 items), access to the inpatient facility of choice (1 item), care around the time of death (6 items), access to home care services (4 items), and access to benefits and services after the patient's death (3 items).

*Results:* Interviews were completed with 524 respondents. In a multivariable linear regression model, after adjusting for the likelihood of receiving a palliative consultation (propensity score), palliative care patients had higher overall scores: 65 (95% confidence interval (CI) 5 62–66) versus 54 (95% CI 5 51–56;  $P < .001$ ) and higher scores for almost all domains. Earlier consultations were independently associated with better overall scores (b50.003;  $P 5.006$ ), a difference that was attributable primarily to improvements in communication and emotional support.

*Conclusion:* Palliative consultations improve out- comes of care, and earlier consultations may confer additional benefit.

**Casarett D., Shreve S., Luhrs C., et al. Measuring families perceptions of care across a health care system: Preliminary experience with the Family Assessment of Treatment at End-of-Life Short Form (FATE-S). J Pain Symptom Manage 2010; 40: 801-809.**

*Context:* Because the Family Evaluation of Treatment at End of Life (FATE) survey was too long for routine use in the Veterans Administration (VA) health care system to measure quality of care, a shorter instrument was developed.

*Objectives:* To evaluate the short version of the FATE survey for use as a nationwide quality measure in the VA health care system.

*Methods:* Fifty-one VA medical centers, including acute and long-term care, participated in this nationwide telephone survey. Family members of the patients were eligible if the patients died in a participating facility. One family member per patient was selected from medical records using predefined eligibility criteria and invited to participate. The survey consists of 14 items describing key aspects of the patient's care in his or her last month of life, one global rating, and two open- ended questions for additional comments.

*Results:* Interviews were completed with 2827 family members. Overall, the survey

showed excellent psychometric characteristics, with good homogeneity (e.g., Cronbach's  $\alpha = 0.84$ ) and strong evidence of discriminant validity. Two survey items have been targeted for quality improvement efforts in multisite collaboratives.

*Conclusion:* Surveys of surrogates offer an important source of quality data that can be used to improve the quality of end-of-life care and promote accountability.

**Casarett D, Smith D, Breslin S et al. Does nonresponse bias the results of retrospective surveys of end-of-life care? J Am Geriatr Soc 2010; 58: 2381-2386.**

*Objectives:* To evaluate the effect of nonresponse bias on reports of the quality of end-of-life care that older adults receive.

*Design:* Nationwide retrospective survey of end-of-life care.

*Setting:* Sixty-two Veterans Affairs Medical Centers.

*Participants:* Patients were eligible if they died in a participating facility. One family member per patient was selected from medical records and invited to participate.

*Measurements:* The telephone survey included 14 items describing important aspects of the patient's care in the last month of life. Scores (0–100) reflect the percentage of items for which the family member reported that the patient received the best possible care, and a global item defined the proportion of families who said the patient received "excellent" care. To examine the effect of nonresponse bias, a model was created to predict the likelihood of response based on patient and family characteristics; then this model was used to apply weights that were equivalent to the inverse of the probability of response for that individual.

*Results:* Interviews were completed with family members of 3,897 of 7,110 patients (55%). Once results were weighted to account for nonresponse bias, the change in mean individual scores was 2% of families reporting "excellent" care. Of the 62 facilities in the sample, the scores of only 19 facilities (31%) changed more than 1% in either direction, and only 10 (16%) changed more than 2%.

*Conclusion:* Although nonresponse bias is a theoretical concern, it does not appear to have a significant effect on the facility-level results of this retrospective family survey.

**Finlay E, Shreve S, Casarett D. Nationwide Veterans Affairs quality measure for cancer: The Family Assessment of Treatment at End-of-Life. J Clin Oncol 2008; 26: 3838-3844.**

The Veterans Affairs (VA) health care system has created a national initiative to measure quality of care at the end of life. This article describes the first phase of this national initiative, the Family Assessment of Treatment at End of Life (FATE), in evaluating the quality of end-of-life care for veterans dying with cancer. In the initial phase, next of kin of patients from five VA Medical Centers were contacted 6 weeks after patients' deaths and invited to participate in a telephone interview, and surrogates for 262 cancer patients completed FATE interviews. Decedents were 98% male with an average age of 72 years. There was substantial variation among sites. Higher FATE scores, consistent with family reports of higher satisfaction with care, were associated with palliative care consultation and hospice referral and having a Do Not Resuscitate order at the time of death, whereas an intensive care unit death was associated with lower scores. Early experience with

FATE suggests that it will be a helpful tool to characterize end-of-life cancer care and to identify targets for quality improvement.

**Alici Y, Smith D, Lu HL et al. Families perceptions of veterans' distress due to post-traumatic stress disorder-related symptoms at the end-of-life. J Pain Symptom Manage 2010; 39: 507-513.**

*Objectives:* To define the frequency of post-traumatic stress disorder (PTSD)- related symptoms among veterans who are near the end of life and to describe the impact that these symptoms have on patients and their families.

*Methods:* Patients had received inpatient or outpatient care from a participating VA facility in the last month of life, and one family member per patient was selected using predefined eligibility criteria. Family members then completed a telephone survey, The Family Assessment of Treatment at End-of-Life, which assessed their perceptions of the quality of the care that the patients and they themselves received during the patients' last month of life.

*Results:* Seventeen percent of patients (89 of 524) were reported to have had PTSD-related symptoms in the last month of life. PTSD-related symptoms caused discomfort less often than pain did (mean frequency score 1.79 vs. 1.93; Wilcoxon sign rank test,  $P < 0.001$ ) but more often than dyspnea did (mean severity score 1.79 vs. 1.73; Wilcoxon sign rank test,  $P < 0.001$ ). Family members of patients with PTSD- related symptoms reported less satisfaction overall with the care the patient received (mean score 48 vs. 62; rank sum test,  $P < 0.001$ ). Patients who received a palliative care consult ( $n = 49$ ) had lower ratings of discomfort attributed to PTSD-related symptoms (mean 1.55 vs. 2.07; rank sum test,  $P = 0.007$ ).

*Conclusion:* PTSD-related symptoms may be common and severe among veterans near the end of life and may have a negative effect on families'.

**De Sousa M, Smith S, Corcoran A et al. Families' perceptions of inpatient and home hospice care at end-of-life. Arch Intern Med 2010; 170(20): 1856-1857.**

Over the past 10 years, studies of end-of-life care in hospitals and long-term care facilities have described a variety of problems. So it is not surprising that many patients say that they would prefer to die at home rather than in a hospital. Indeed, one national study of end-of-life care found that home hospice care produced higher family ratings of care compared with inpatient care.

However, the landscape of inpatient care is changing rapidly, and many hospitals have created palliative care consulting services and specialized inpatient palliative care units. It is important to determine whether inpatient palliative care offers a high-quality alternative to home hospice care because a death at home is not possible for all patients.

**Lu H, Trancik E, Bailey FA et al. Families' perceptions of end-of-life care in Veterans Affairs versus non-Veterans Affairs facilities. J Palliat Med 2010; 13(8): 991-996.**

*Background:* The Veterans Affairs (VA) has made significant investments in care for veterans. However, it is not known whether these investments have produced improvements in end-of-life care in the VA compared to other settings. Therefore, the goal of this study was to compare families' perceptions of end-of-life care among patients who died in VA and non-VA facilities.

*Design:* Retrospective 32-item telephone surveys were conducted with family members of patients who died in VA and non-VA facilities.

*Setting:* Five Veterans Affairs medical centers and their affiliated nursing homes and outpatient clinics.

*Participants:* Patients were eligible if they received any care from a participating VA facility in the last month of life and if they died in an inpatient setting. One family member per patient completed the survey.

*Results:* In bivariate analysis, patients who died in VA facilities ( $n = 520$ ) had higher mean satisfaction scores compared to those who died in non-VA facilities ( $n = 89$ ; 59 versus 51; rank sum test  $p = 0.002$ ). After adjusting for medical center, the overall score was still significantly higher for those dying in the VA ( $\beta = 0.07$ ; confidence interval [CI] = 0.02-0.11;  $p = 0.004$ ), as was the domain measuring care around the time of death ( $\beta = 0.11$ ; CI = 0.04-0.17;  $p = 0.001$ ).

*Conclusion:* Families of patients who died in VA facilities rated care as being better than did families of those who died in non-VA facilities. These results provide preliminary evidence that the VA's investment in end-of-life care has contributed to improvements in care in VA facilities compared to non-VA facilities.

**Smith D, Caragian, N Kazlo E et al. Can we make reports of end-of-life care quality more consumer-focused? Results of a nationwide quality measurement program. J Palliat Med 2011; 14: 301-307.**

*Objectives:* The goal of this study was to define families' priorities for various aspects of end-of-life care, and to determine whether scores that reflect these priorities alter facilities' quality rankings.

*Design:* Nationwide telephone survey.

*Setting:* 62 VA medical centers, including acute and long term care.

*Participants:* For each patient who died in a participating facility, one family member was invited to participate.

*Measurements:* A survey included 14 items describing key aspects of the patient's care in his or her last month of life, and one global rating. A weighted score was calculated based on the association between each item and the global rating.

*Results:* Interviews were completed with family members for 3,897 of 7,110 patients (55%). Items showed an approximately 5-fold range of weights, indicating a wide variation in the importance that families placed on aspects of palliative care (low: pain management, weight = 0.54, 95% CI 0.38-0.70;  $P < 0.001$ ; high: providers were "kind, caring, and respectful: weight = 2.46, 95% CI 2.24-2.68;  $P < 0.001$ ). Weights were homogeneous across patient subgroups, and there were no significant changes in facilities' quality rankings when weights were used. Both weighted and unweighted

scores showed similar evidence of the impact of process measures.

*Conclusion:* There appears to be wide variation in the importance that families place on several aspects of end-of-life care. However, the impact of weighting was generally even across patient subgroups and facilities. Therefore, the use of weights to account for families' priorities is not likely to alter a facility's quality score.

**Casarett D, Johnson M, Smith D, Richardson, D. The optimal delivery of palliative care: A national comparison of the outcomes of consultation teams vs inpatient units. Arch Intern Med 2011; 171(7): 649-655.**

*Background:* Growing attention to end-of-life care has led to intensive efforts to provide better palliative care. However, it is not known whether palliative care is best provided by consultative teams or in dedicated units.

*Methods:* This nationwide telephone survey was conducted in 77 Veteran Affairs medical centers that offer palliative care consultation services and dedicated palliative care units. One family member per patient who died at a participating Veterans affairs medical center between July 1, 2008, and December 31, 2009, was invited to participate. The telephone survey included 1 global rating item and 9 core items describing care in the last month of life.

*Results:* Interviews were completed with family members for 5901 of 9546 patients. Of these, 1873 received usual care, 1549 received a palliative care consultation, and 2479 received care in a palliative care unit. After nonresponse weighting and propensity score adjustment, families of patients who received a palliative care consultation were more likely than those who received usual care to report that the patient's care in the last month of life had been "excellent" (adjusted proportions: 51% vs 46%; odds ratio [OR], 1.25; 95% confidence interval [CI], 1.02-1.55;  $P = .04$ ). However, families of patients who received care in a palliative care unit were even more likely to report excellent care (adjusted proportions: 63% vs 53%; OR, 1.52; 95% CI, 1.25-1.85;  $P < .001$ ).

*Conclusion:* Care received in palliative care units may offer more improvements in care than those achieved with palliative care consultations.